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ABSTRACT

Demographic changes, changes in women's work roles, and changes in the nature of the family have increased the importance of identifying the effects of government policy on family cohesion and living arrangement decisions. The effect of public policy on the nation's largest source of caregivers, the family support system, is a key issue. While there appears to be considerable interest in promoting and fostering the ability of families to care for their aged members, there is considerable confusion about how this goal can best be accomplished. Policy recommendations which favor funding and services to families rather than promoting institutional care include ongoing funding for respite care, increased adult day health facilities, financial incentives to families, flexible work schedules, education, and advocacy. A recurrent theme in the literature addressing policy issues in providing help to older adults is the respective roles of the informal and the formal support systems. Government programs should be designed to supplement and support, rather than substitute for, family care. (NB)

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SOCIAL POLICIES FOR FAMILY CAREGIVERS[1]

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ABSTRACT

The effects of current trends and existent government policy on family caregivers to the elderly are examined. Policy recommendations which favor funding and services to families rather than promoting institutional care include: ongoing funding for respite care, increased adult day health facilities, financial incentives to families, flexible work schedules, education, and advocacy. Government programs should be designed to supplement and support, rather than substitute for, family care.

Key words: Frail elderly, long-term care, formal and informal support.

SOCIAL POLICIES FOR FAMILY CAREGIVERS

Changes in the country's demographics, women's work roles and the nature of the family have increased the importance of identifying the effects of government policy on family cohesion and living arrangement decisions. The effect of public policy on the nation's largest source of caregivers - the family support system - is a key issue. Many families are under considerable stress as they seek to remain intact and to cope with the problems of aging parents.

Filial responsibility is a controversial issue in public policy. A review of legislation in this area reveals that as of 1975 filial support statutes still existed in 25 states and the opportunity to apply these statutes to particular assistance programs still exists. In assessing these laws Newman (1980) concludes that "these laws are at best, an irritant, and at worst, damaging to whatever family ties do exist." Others agree in strongly opposing these requirements, based on the negative effects of responsiblity laws on family relationships and duties. The consensus is that contributions of support, be they financial or in-kind, are a function of people's feelings for one another and that affection and concern are prerequisites for any exchange of aid. Government may be able to strengthen ties that are already strong, but it is unlikely that they can be legislated into existence (Newman, 1980). It is acknowledged that there is considerable interest in promotoing and fostering the ability of families to care for their aged members, but there is also considerable confusion about how this goal can best be accomplished.

Attempts to pass federal filial support legislation have surfaced in congressional sessions since 1975 and can be divided into two categories: proposals requiring payments by adult children to support their aged parents and proposals for the government to subsidize family care of the elderly. If adult children and their parents have mutually agreed that family care is best but are prevented from providing it due to lack of adequate finances, then subsidies could potentially increase the number of aged parents receiving family care. However, not without hazards, as it is most likely that family care subsidies would be subject to the same administrative and regulatory problems that plague other entitlement programs.

Another consideration which would come into play in deciding whether or not the cost of a subsidy program for family care is justifiable, is its ability to neutralize the institutional bias of current government policies regarding the long-term care of the elderly. The most important programs affecting the lives of older Americans, other than Social Security, are Medicare and

Medicaid. Medicare and Medicaid appear to translate into an anti-family pro-institutional bias by forcing the decision to choose institutional care as a way to obtain ongoing and presumably comprehensive care which is reimbursable, not because the elderly person's physical condition warrants it, but because there is no other viable way to afford the part-time but wide-ranging care that is needed. As a general rule family members cannot receive reimbursement as caregivers under the home health care sections of either Mediare or Medicaid. Under Medicare, this possiblity is limited by the "skilled nursing requirement," and under Medicaid, the home health provisions prohibit "relatives" from providing reimbursable care. In practice, this amounts to a systematic bias against family support and care (Newman, 1980).

Incentives to family units could be used as alternatives to institutionalization of the aged family members. Sussman (1976) suggests that while many families are willing and able to provide care to elderly kin now, others might do so if various supports were available to mitigate the stresses that such care involves. The incentives to the family providing care could be designed contractually during a given time and involve such benefits as a direct monthly allotment of funds; specific tax write-offs for expenses involved; a loan to add to or renovate a house so as to offer convenient and independent living for the old person; income tax relief for taking on the responsibility of care; access to particular services, for example, providing for day care and home-bound services, that are needed or helpful to the caretaking family', and property tax reduction propotional to dwelling use of caretakesrs. These incentives, suggested by Sussman, could relieve a family's dwindling resources and remove impediments to aiding its elderly members. By removing economic liabilities from the caregiver and offering instead a reward, modern family responsibilty could be stimulated. Families need relief from the crushing burdens experienced in providing continuous care for elderly members. This relief might be delivered through a combination of policy iniatives.

RESPITE CARE AND FAMILY SUPPORT

With the growing number of chronicaly ill elderly and the rising costs of hospital and nursing home care, increased consideration is being given to alternatives for providing long-term care services in order to prevent the need for institutionalization. One alternative is to provide respite care to relieve family caretakers for a period of time. Respite care consists of the delivery of support services to family members who are caring for an elderly person in the home. The purpose is to give caregivers a respite from their responsibilities. The care may also be provided in a crisis. Respite care may be based in the home or in a facility and may be medical, or social in

nature. The time frame for services ranges from 2 - 4 hours, once a week, to 2 or more weeks of 24 hour care.

Respite care provided in the home is for families who care for the chornically ill at home and need time off, just like any other caregiver. These programs 'take-over' temporarily with the health care procedures ordinarily carried out by the caregiver assumed by the respite worker during the caregiver's absence (Hildebrandt, 1983). Other respite care programs include individuals staying in nursing home based respite quarters with service financed through fees paid by the patient's family, ranging from $55 - $65 per day (Ellis & Wilson, 1983), or, respite care programs have been developed as demonstration projects in a Veterans Administration Hospital or State-owned hospital (Huey, 1983). Tremendous demands exist for respite care and it is said that "respite care may be the best kept secret in the care of families of the frail elderly."

In this time of economic hardship when government spending is being carefully examined, it appears that respite care is a wise investment. It can delay nursing home admission of the frail edlerly, help keep families together, and keep governmental cost to a minimum (Hildebrandt, 1983). Ongoing sources of dependable funding - such as coverage by medical or long-term care insurance plans - are essential if there are to be respite programs on a national basis. There is little doubt that readily available respite care would be a significant contribution to keeping frail elders in the community. New models, such as "night sitting services," "go to bed patrol" and "assisted lodging" now in use abroad should also be attempted (McFarland, Howells & Dill, 1985). As Ward (1978) states, programs should aim to support the role of the family by providing assistance in the form of money and services. To simply rely on the family to fill the gap without supporting its role can only weaken its ability and willingness to do so.

CAREGIVER CHARACTERISTICS

Who are the caregivers? The largest number of sick and impaired elderly living in the community are cared for by a spouse. Although retirement and widowhood or widowerhood are recognized as difficult life transitions, less attention has been given by professionals to the period of extended functional decline among elderly spouses. With illness and chronic impairments, elderly spouses often experience rapid shifts in demands to meet the day-to-day needs of caregiving. The strain on caregiving spouses has been documentd by Arnold Golodetz (1969) who found that caregiving wives often had serious illnesses and were severely limited in meeting their own needs and activity requirements. Although the presence of a spouse may forestall or avoid insitutionalization, it may also be at considerable cost to the caregiver.

Failing the ability of a spouse, adult daughters or daughter-in-laws take over caregiving duties. It is women in our culture who are socialized to assume a nurturing and affiliiational role in relation to holding their families together and thus they inherit the duties of providing personal services such as bathing, dressing, toileting and feeding the elderly parent, as well as running errands, shopping, escorting to medical appointments, while it is the sons who take over financial matters. Both offspring are hindered in their ability to meet their aging parents needs, by their own familial obligations and personal limitations. Strain is experienced in time, finances, physical resources and emotional resources, particularly by adult duaghters who increasingly face employment responsibilities as well as domestic tasks (Treas, 1977).

It must be noted that the combination of women at work and parent care means not a redistribution of tasks but a larger package of responsibilities to be distributed. Furthermore, the family's willingness to care for its old, to sacrifice their own lives to help the aged, must be measured overall against the capacity of current and future caregivers to provide the needed help. Current enthusiasm for alternatives to institutionalized care of the aged must be tempered by realistic expectations of the willingness and ability of modern American women to provide continued services for aging kin. The care of aging parents is but one of a number of competing responsibilities confronting mature women (Treas, 1977) who have been variously described as the "sandwich" generation, or "women in the middle."

WOMEN IN THE MIDDLE AND WORKPLACE POLICIES

As Brody (1981) describes them, these "women in the middle" are women who are middle age, middle generation, middle in the demands of their various roles which compete for their time and energy, and in the middle of competing values, that is, the tradition that care of the elderly is a family responsibility versus women should be free to work outside the home if they wish. Work outside the home is not always a choice and women who provide their own sole support and perhaps the support of their children are not in a poisiton to jeopardize their livelihood by taking time off from work to help eldelry parents. For these women attempts to juggle home, family, job and care for parents may become highly stressful (Cicirelli, 1981).

Work itself does not seem to be a reason for relinquishing responsiblity to the elderly, but job performance may be affected by the emotional stress and time pressures involved in providing primary care to a frail older person. Flexibility in the work place could ease that strain and at the same time positively affect employee productivity. Employers should be encouraged to

consider flexible work schedules and compensatory time off both for the care of children and for the care of an aged parent. As Treas (1977) points out, if young women are willing to delegate some responsibility for child care, adult daughters will be willing to do so for parent care. Yet attitudes about providing services to help families with their old are often sanctimonious and judgemental. The lag between needs and family-oreinted programs is great. The call of young women for modifications in the work place, such as flex-time, flexible job definitions, and child care provisions, can be echoed by women in their middle years.

Given the facts that 60% of women between the ages of 45-54 now work, as do 42% of those in the 55 - 64 age broup (Federal Council on Aging [FCA], 1984), employers should not consider themselves to be immune from the problems of family caregivers. The joint demands of caregiving and employment often exercise a negative influence on one another. Recently the Federal Council on Aging called together experts to discuss supporting caregivers of the elderly through the workplace. It was suggested that by offering caregiver support in the workplace, the employer would experience resultant benefits in reduced absenteeism, more work focused employees, and improved job performance. One of the conclusions of the symposium was that the workplace could serve as an effective practical and accesible dissemination point for caregiver information and support, and that the workplace could take a leadership position in linking the informal and formal systems (FCA, 1984).

The workplace seems an appropriate setting for offering assitance to caregivers as well as linking them to the formal system. As a specific example, through the workplace, employees could be informed of the Dependent Care Tax Credit for Adult Care expenses. This is especailly applicable since the tax credit is for work-related expenses for the care of an adult member of the household who is incapable of self-care. Workers frequently lack knowledge of the details of the tax credit, who can use it, how it works, what are the limits of the amount of expenses that can be claimed, and the like. The workplace can be an appropriate point to begin dissemination of information on older American issues, and a progressive step towards improving the quality of life of the older adult and his/her caregiver.

CAREGIVERS AND SUPPORT GROUPS

Moving away from caregivers in the workplace, Shanas (1979) describes the generation in the middle as having to balance the demands of an aged parent with those of adult children and grandchildren at a time when their own energy level, health status and financial status may be declining. In contemporary society, the very old who are in greatest need of care have offspring who are the 'young-old' with their declining energy, health and finances. To quote a 64 year old daughter of an 88

year old woman, "Both my husband and I are ready for a little peace and quiet. Mother is thinking that I'm 40 again and can run around for her - I'm tired now. She's unable to think of us as senior citizens." Many family caregivers of the elderly are old themselves and vulnerable to chronic health problems. These people warrant special attention in the development of any policy directed at family caregiving. Efforts to assist family caregivers should give special attention to those situations involving older persons aged 85+ because of the relatively large burden placed by people in this age group on their children and because of the age of their caregiving children (New York State Office fo the Aging, 1983).

Evidence suggests that breakdowns may be influenced as much by changes in the status of the caregiver as in the care-recipient. Coping with a deteriorating aged parent or spouse produces a stressful situation. The caregiver, ill prepared for the great demands placed on him/her, and heretofore unrecognized fear of personal aging ("Dear Lord, keep me from being like that when I'm aged"), not only become jailers but are in jail themselves (Rathbone-McCuan and Hashimi, 1982). How people cope with this aspect of family life is very private with an invisible quality to the struggle. Elders are cut off from others and their only link to the outside world is controlled by their caregiver. Under conditions of extreme stress linked to caregiving, abusive behavior may take place. Violence and abuse are among an infinite range of possible coping behaviors that arise in such situations. Absence of community resources to assist the caregiver in caring for the elderly patient can lead to an expression of frustration through violent behavior.

A consistent finding of recent research in social gerontology has been the importance of the family as a source of support for older Americans. There appears to be an increasing need for relatives who have a caretaking role with older adults to have some assistance with handling their feelings, their realistic planning, their understanding of aging and support for their day to day responsibilities and frustrations. "My mother can get me riled up more than anyone - always has. I guess that's a mother-daughter relationship. As much as I know she can't help it, I get so angry inside that I can hardly control myself."

The effective management of health problems of older adults depends greatly on the provision of assistance to them by their family members. It has been posited that eduction and support groups can enable these family members to better carry out their responsibilities (Clark & Rakowski, 1983). The toll of caregiving appears to be high. Family members who provide care make personal sacrifices yet feel guilt, resentment and even hositiliy. They often experience feelings of burden and stress and generally have low morale. As one caregiver expressed it, "once in a while I take the phone off the hook and rest or don't answer it. I take a day off 'to be good to myself'."

It is not uncommon for family members to give up their jobs to care for the ill relative and for their own health to deteriorate. Nationally a number of eduction and support groups have been initiated with a focus on mutual aid, self-awareness, increased knowledge of aging, access to formal supports, and socialization. These groups can be a helpful means of enabling caretakers to be able to function adequately and to improve the quality of life for older adults and their families (Hartfod & Parsons, 1982).

A CAREGIVERS SUPPORT GROUP MODEL

Social support groups generally serve three main functions: education to provide information, support to alleviate psychological and environmental stress, and advocacy to promote lobbying for legislative changes. The recognition of the lack of willingness of caregivers to seek help can be a factor in organizing these groups. Outreach to the community is often necessary. A point of entry could be to form a caregivers' group within a community hospital setting where elderly patients are being treated. Other hosts for caregivers' groups could be existing agencies, such as a community's family service agency, a parochial or ethnic social service agency, a senior citizens center, or, as the Federal Council on Aging (1984) has indicated, various workplaces.

In terms of intervention directed towards the caregiver, the education component of support groups includes:

1. Providing knowledge of available resources in the community, such as home health care agencies, community support services, or respoite care.
2. Training in the competence and skills necessary for caregivers of impaired elderly to navigate the social service bureaucracy in the community and to interact more effectively with the health care system.
3. Providing practical information such as medication regimens and drug interaction effects in older adults; paramedical skills, such as CPR; handling Medicare and other insurance forms; and, understanding problems of relocation for the elderly.

The peer support component deals with concerns, difficulties, successes and individual counselling where indicated. This component involves:

1. Discussion of the biological, social and psychological aspects of aging; the behavior problems and characteristics of the frail elderly; and, changes in family relationships among caregivers, elderly, and other relatives.
2. Normalization of the role of caregiving. This is a new

role for which there is no previous role model from the older generation. Roles as paid workers and as caregiving daughters and daughter-in-laws have been added to the traditional roles as wives, homemakers, mothers, and grandmothers. ("A number of my friends are going through this. My mother never had to cope with an elderly parent. we're all wondering how to handle it.")

3. Counselling to deal with feelings of frustration, guilt, anxiety, impatience, anger, entrapment, and to help face the issues of illness and death of a loved one. ("it would be a blessing if she'd just die suddenly rather than go on as she is.")

The third function of support groups involves advocacy. In addition to being a vital source of direct assistance to the aged, the family performs indirect functions. Sussman (1976) describes that family members often serve as unobtrusive mediating links between older individuals and society institutions and organizations, acting as advocates, and as a resource for information on the rights and entitlements of aged relatives. There is a crucial need to advocate for changes to modify the bureaucractic system so that it meets the needs of the elderly in a way more satisfactory to both the old people and their kin (Shanas, 1979).

FAMILY ADVOCACY

A national organization linking support groups of family caregivers can form an effective lobby for promoting family care for the elderly in their own home, rather than money being allocated towards institutionalization. United, family caregivers can make a big difference. Advocacy would include lobbying for increased support services to the frail elderly, that is, increased respite, increased adult day health facilities and increased financial incentives and reimbursements to family caregivers. Several authors have noted that fmaily members role as mediators between the aged and the public service system will probably become increasingly important. It is not just a mediating link that is needed, but activism. The critical importance to society of caregiving activity by family members must not be underestimated.

Certainly advocacy on behalf of the frail elderly is relevant and current. Opinions range, however, as to which policy issues ought to be addressed. Public policy concerned with the economic well-being of the aged has been so highly developed over hte last quarter century that it has now become a central topic of debate. Consequently the total amount of funds to be appropriated for long-term care remains a contested issue. According to Estes (1979), the allocation of more federal resources for the elderly will create or contribute to intergenerational conflict. A large segment of the public is now calling for limits on the cost of government and the role of

government in the lives of individuals.

Sager (1983) argues that as they heed this call, politicians are increasingly reluctant to pass new spending measures for the benefit of the aged. In spite of the overwhelming public preference for non-insitutional long-term care of the elderly, Sager suggests that Congress is in no rush to enact any of the proposed legislation to expand home care and related services.

STATE AND FAMILY CARE; REVISING THE CONTRACT

In summation, what are the public policies that are being called for by the experts? The goal is to achieve a balance between the provision of bureaucratic support for the family and the maintenance of family mutual support networks. An example of a progressive policy is California's modification under Title XX allowing recipients to purchase services relating to homemaking chores from their relatives. According to a study by Pruger and Miller (1977), such services by relatives was most preferred by recipients and was the least expensive method of delivering the services. Sager (1983) enumerates a number of poicy alternatives which include:

1. Financial aid, on a sliding scale, to families providing support for aged members.
2. Flexible work schedules to enable families to provide support to the aged.
3. Income tax credits for elder care.
4. Day care and day health programs for frail elderly.
5. Supportive services for the family network.
6. Information and resources furnished to adult children.
7. Elimination of SSI and Medicaid regulations that restrict family involvement.

Sager concludes that government needs to foster family self-help with an incentive-based system of supports so that government services are not in competition with family mutual support systems. Getzel (1981) confirms that social policies must provide incentives and recognition to families' contributions to elderly relatives. As Shanas and Maddox (1976) point out, home care provided by family members has been treated as though it had no economic cost, although the cost of publicly financed home care programs is demonstrably high. In an era of increasing budgetary limitations, formal home care programs should seek to supplement and enhance the operation of informal support systems rather than provide a range of substitute services.

A recurrent theme in the literature addressing policy issues in providing help to older adults is the respective roles of the informal support system and the formal support system. Treas (1977) offers that,

State and federal programs might consider the wisdom of direct subsidies to families who participate in the day to day care of aging relatives. Families who overcome the many obstacles to home care of the aged would seem to warrant direct payments as surely as do strangers providing less personalized services.

These recommendations echo Sager's call for tax breaks, special allowances to help defray parent-care costs, and direct reimbursements to family caretakers so as to promote those kin ties which are so threatneed by social and demographic change. Brody's position is that as long as social policy continues to give only lip service to family policy that would help the elderly, all generations are at risk, for their well-being is interlocked.

It is clear that the "mix" of formal and informal supports must change. Social policy must move virogously to implement a family oriented policy to support the informal system (Brody, 1981). There are no replacements for families. As Rosow (1974) observes, our society's commitment to "family" can best be expressed by buttressing the family's capacity to help its old, that is, by providing services in ways that focus on the needs of the total family. The overwhelming preference for children as sources of affective support is a reminder of the conitnuing emotional interdependence of family members for which no bureaucaratic arrangement can offer a substitute. Social policy must address the needs of the total family. What needs to be negotiated is a "revised contract" between the family as a whole and the formal support system that only social policy can create (Brody, 1981).

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